

# Public Health Data Resource Guide 2005

This report was prepared by  
Kentucky Cabinet for Health and Family Services  
Kentucky Department for Public Health  
Data Users' Workgroup

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## Introduction

Public health data form the foundation for all that is accomplished in public health. Valid and reliable data are necessary to adequately monitor the health status of our community and evaluate our public health programs. There are a variety of resources specific to Kentucky that provide public health data for program monitoring, assessment, and evaluation. Identifying and providing easy access to these resources are essential for effective public health decision making and research.

The Kentucky Department for Public Health Data Users' Workgroup began coordinating this guide early in 2005. The workgroup identified the data resources to be described and asked the data source contacts to provide specific information for the guide.

A variety of health-related surveys that collect statewide data are described in this guide, as well as Kentucky-specific surveillance systems and registries. The types of data collected are included as well as strengths and limitations of each data source. Contact information is provided for every source and most contain web links for easy access to available data.

The Data Users' Workgroup created this guide to promote access to public health data; however, some data sources are highly confidential and cannot be released to the public. Program coordinators and data analysts follow HIPAA guidelines when disseminating data. As a result, full data sets may not be available for all data sources presented. Data summaries and reports should be available for most data sources.

While many data sources are included, certain resources were not available for this year. For instance, Kentucky's Newborn Screening Program has increased from four to 29 the number of metabolic conditions that it monitors. The program will need to evaluate its new data collection system before data will be released to the public. This surveillance system will be included in future data resource guides. Additionally, contact information for Medicaid-related data will be available to include in the next edition.

This guide is a valuable resource for conducting public health research, monitoring public health goals or objectives, evaluating initiatives, or exploring Kentucky-related data sources. To recommend other useful and essential data sources for inclusion in future editions, please send a response to Sara Robeson, Division of Epidemiology and Health Planning, (502) 564-3418 extension 3567. Additional suggestions to make this guide more useful are welcome.

## Behavioral Risk Factor Surveillance System (BRFSS)

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**State Web Site:**

<http://chfs.ky.gov/dph/epi/BRFSS.htm>

**National Web Site:**

<http://www.cdc.gov/BRFSS>

### Sources of Information for the BRFSS

The Behavioral Risk Factor Surveillance System (BRFSS) is a telephone health survey co-sponsored by the Centers for Disease Control and Prevention (CDC) and the Kentucky Department for Public Health. The survey is randomly administered to non-institutionalized civilian adults age 18 or older who are living in a household with a telephone. Participation in the survey is strictly voluntary. Personal identifying information, such as name or address, is not collected. The Kentucky BRFSS has been conducted continuously since 1985 and is located organizationally in the Cabinet for Health and Family Services, Department for Public Health, Division of Epidemiology and Health Planning.

### Description of Data Collected

The BRFSS collects data on risk factors, health behaviors, chronic disease prevalence, and preventive health measures. Some recent topics include tobacco use, alcohol consumption, influenza immunization, diabetes prevalence, asthma prevalence, hypertension awareness, HIV/AIDS, colorectal cancer screening, breast cancer screening, cervical cancer screening and weight control. Demographic data collected include gender, age, race, ethnicity, income, education level, employment status, and county of residence. The survey has three types of questions: Core, Module, and State Added. Core questions are asked by all states. Module questions are groups of questions on particular topics developed by the CDC that states may decide to include on the questionnaire. State added questions are questions that states may develop or obtain that relate to the public health needs of their state.

## Data Set Availability

Kentucky BRFSS data from 1985 to the present are available to the public in yearly data sets. The statewide data are available in both SAS and comma delimited formats. A weighting variable is included in the data sets so that prevalence estimates can be generalized to the statewide population. Contact the BRFSS coordinator if requesting Kentucky aggregated data or raw data sets. National data are available on the national BRFSS web site.

<b>Average Yearly Sample Size</b>	7500
<b>2003 CASRO Response Rate</b>	61.9%
<b>Smallest Geographic Level Released</b>	County
<b>Data Format</b>	SAS, comma delimited
<b>Cost of Data Set</b>	Free

## Data Publications

The BRFSS program produces a yearly statewide summary including an analysis of over 25 risk factors and health behaviors by demographic variables and Area Development District (ADD). From 2000 to the present, yearly data for almost every question on the survey can be found on the Kentucky BRFSS web site:  
<http://chfs.ky.gov/dph/epi/BRFSS.htm>.

## Data Limitations

There are two main limitations to BRFSS data, non-coverage bias and self-report bias. These limitations should not hinder the use of BRFSS data but should be considered.

**Non-coverage Bias:** According to the 2001 Census Population Estimate, 6.5% of Kentuckians were without telephones. This population is not reached, and could have socioeconomic differences from the survey population.

The BRFSS only surveys adults in households. No person would be surveyed who lived in any type of group setting, such as a nursing home, college dormitory, the military, or prison.

**Self-report Bias:** The BRFSS survey relies on self-report. That means that the prevalence estimates are strictly based on each respondent's answers to the questions. The tendency to report a healthier lifestyle may occur.

### Strengths of the Data

The BRFSS provides data on risk behaviors, preventive health practices, and chronic disease prevalence that are not collected by other surveys or surveillance systems. The BRFSS sample size is large enough to provide yearly prevalence estimates by ADD. The data are very timely as well. Data are usually available within six months of the data collection year. For example, data from survey year 2003, were available by June 2004. The survey is conducted by all states, Washington D.C., and certain territories; therefore, data from Kentucky may be compared to other states.

### Specific Uses of Information

- Monitor *Healthy Kentuckians 2010* goals
- Provide data to create and evaluate prevention and treatment initiatives many public health programs including tobacco, diabetes, asthma, women's cancer screening, folic acid, and family planning
- Provide the groundwork for the Department for Public Health's obesity prevention initiative and publications, *The Kentucky Obesity Epidemic, 2004* and *Close to the Heart of Kentucky, 2004*
- Provide data for grant applications related to diabetes, asthma, obesity, HIV/AIDS, tobacco and family planning
- To evaluate health disparities

### System Evaluation

The data collection is routinely monitored utilizing quality control standards developed by CDC. Evaluation of quality is determined through monthly and annual reports of these performance standards.

### Suggested Data Citation

Kentucky Department for Public Health (KDPH) and Centers for Disease Control and Prevention (CDC). *Behavioral Risk Factor Surveillance System Survey Data*. Frankfort, Kentucky: Cabinet for Health and Family Services, Kentucky Department for Public Health, [survey year].



## Central Nervous System Injury (CNSI) Surveillance Project

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**State Web Site:**

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**National Web Site:**

<http://www.cdc.gov/node.do/id/0900f3ec8000dbdc>

### Sources of Information for the CNSI

The Central Nervous System Injury (CNSI) Surveillance Project is funded by the Kentucky Traumatic Brain Injury Trust Fund Board. Its purpose is to track cases of traumatic brain injury, spinal cord injury, and acquired brain injury as defined by the Centers for Disease Control and Prevention (CDC) and the Kentucky Revised Statutes (KRS 211.470). Cases are taken from three sources. Inpatient hospitalizations for CNSI are ascertained using the Kentucky Hospital Discharge Database (HDD) and the Kentucky State Trauma Registry Database. The latter is maintained by the Kentucky Injury Prevention and Research Center (KIPRC). Fatalities are obtained from the National Center for Health Statistics' annual Multiple Cause of Death (MCOB) files. These three sources are linked to resolve duplication of cases across databases, using a probabilistic methodology based upon research by Fellegi and Sunter (1969) and Jaro (1985, 1995).

### Description of Data Collected

Data are collected on the injured person's demographics (age, gender, county of residence), cause of injury (mechanism, manner, and external cause of injury code), injury severity (fatality indicator, injury severity score, length of stay in hospital, and disposition at discharge), and diagnoses, as well as the hospital name, payers billed, and total charges billed for those who were hospitalized.

### Data Set Availability

KIPRC's data use agreements for the hospital discharge and MCOB databases do not permit us to release case-level data from the CNSI database. Aggregated (tabular) data may be requested by contacting the project coordinator.

### Data Publications

KIPRC has published a report of the *Traumatic Brain Injury and Spinal Cord Injury Project* annually since 1998. The fiscal year 2004 report describes injuries that occurred in 2001. Copies can be obtained by contacting the project coordinator.

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## Public Health Data Resource Guide

## Data Limitations

There are two main limitations to the CNSI data:

**Incompleteness of residence data:** Because the MCOD files are based on cases collected under Kentucky's Vital Statistics Surveillance System (KVSSS), collection of fatal CNSI cases is subject to the incompleteness problems outlined in the chapter on KVSSS. Also, the HDD does not capture Kentucky residents who are treated in out-of-state hospitals, including those treated for CNSI.

**Timeliness:** The MCOD file for a given year is typically not available until 18 months after the end of that year. For example, the 2003 state-specific files will be released around August 2005. This is why the fiscal year 2004 Kentucky CNSI report was based on 2001 calendar year data.

## Specific Uses of Information

- Annual CNSI surveillance report
- Ad-hoc data requests and reporting

### Strengths of the Data

The MCOD and HDD files are population-based rather than relying on a sampling strategy. We have followed, to the extent possible, the CDC's *Central Nervous System Injury Data Submission Standards – 2002*. This is a widely accepted standard, meaning that Kentucky's results are comparable to those of many other states who do CNSI surveillance.

## System Evaluation

The MCOD files are based on death certificate files provided to NCHS by the KVSSS, so evaluation measures described under that system's entry apply to this system as well. A detailed evaluation of the CNSI surveillance system to be undertaken in 2005 will focus on the linkages of the individual databases. Such a study will enable us to assess the concordance of data elements across systems, as well as identify possible gaps in case reporting in the individual systems.

## Suggested Data Citation

Kentucky Injury Prevention and Research Center (KIPRC). *Central Nervous System Injury Surveillance Project*. Lexington, Kentucky: University of Kentucky [data year].

## References

Fellegi IP, Sunter AB. *A theory for record linkage*. Journal of the American Statistical Association, 1969; 64(328):1183-1210.

Jaro M. *Advances in record linkage methodology as applied to matching the 1985 census of Tampa, Florida*. Journal of the American Statistical Association, 1989; 84(406):16-21.

Jaro M. *Probabilistic linkage of large public health data files*. Statistics in Medicine, 1995; 14:491-498.

## Child Fatality Review (CFR)

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**State Web Site:**

<http://chfs.ky.gov/dph/ach/childfatality.htm>

### Sources of Information for the CFR

The Child Fatality Review (CFR) program is a passive surveillance system that reviews all child deaths aged 0-17 in Kentucky. The system is designed to provide information on incidence, prevalence, and trends of causes of death to Kentucky's children. The CFR is located organizationally in the Cabinet for Health and Family Services, Department for Public Health, Division of Adult and Child Health Improvement, Maternal and Child Health Branch.

### Description of Data Collected

The CFR collects information from vital records and coroner report forms on all Kentucky resident children from birth to seventeen years of age who die from any cause of death. Data are also provided to the CFR from the Department for Community Based Services regarding substantiated cases of child abuse and neglect to Kentucky's children. Vital records are accessed on a monthly basis and coroner report forms are mailed in as soon as they are completed and subsequently entered into the CFR database. Personal identifying information, cause of death codes, and circumstances surrounding the death are collected by CFR, and it is therefore considered a highly confidential database. Due to the sensitive nature of the data and laws designed to protect the individual, no personal identifying information is released from CFR, and data are only presented/released in aggregate fashion. The lowest demographic level of information that can be provided by CFR is the Area Development District level; county level data are **not** available.

### Data Set Availability

CFR data from 2000 to present are available to certain individuals provided an institutional review board (IRB) approval to access the data has been obtained. CFR staff reserve the right to deny any data request they deem would violate state and or federal laws governing the data set. The data set is only available in aggregate form and NO identifying information will be released to any requestor under any circumstances.

### Data Publications

The CFR produces an annual report that contains trend data on causes of death to children aged 0-17. The data are broken out by cause of death, age, sex, and race. The report is produced in printed format as well as placed on the CFR web site.

### Data Limitations

There is one main limitation to CFR data; small numbers when dealing with individual causes of death. As a result, data must be presented in an aggregate fashion and cannot be provided by county level. Also, the sensitive nature of the data plays a role in what can and cannot be released to data requestors. This limitation should not hinder the use of CFR data but should be considered.

Two other limitations that CFR is working to correct include: capturing out-of-state deaths to Kentucky residents, not all cases are being captured in CFR, and currently CFR does not have the capability to link death records electronically with coroner report forms.

### Strengths of the Data

The CFR provides data on causes of death and circumstances surrounding the death as well as recommendations for prevention education and awareness. The CFR is a state-wide program with data analysis and reporting occurring on an annual basis. Data are readily accessible only by two full-time staff members in the MCH branch and are updated on a monthly basis. Data provided to CFR occurs in a relatively timely fashion with coroner report forms being submitted as soon as the investigation is complete and vital records being reviewed on a monthly basis.

### Specific Uses of Information

- Monitor *Healthy Kentuckians 2010 Goals*
- Monitor KIDS NOW Initiatives on Early Childhood Development
- Provide data for use in various projects
- Data are used to monitor select performance measures for the Title V Federal Maternal and Child Health Block Grant
- Evaluate health disparities

Data are used annually to monitor trends of child deaths among specific populations, geographical areas, and the state as a whole and to monitor any cluster of specific causes of death.

### System Evaluation

Data collection for CFR is monitored on a quarterly basis with review of the coroner report forms to ensure proper notification to reporting agencies (i.e. Local Health Departments, Law Enforcement, and Department for Community Based Services) when a child death occurs. Death certificates from vital records are also reviewed to determine any discrepancies or omissions.

**Suggested Data Citation**

Kentucky Child Fatality Review Data, (Year); Kentucky Department for Public Health, Division of Adult and Child Health Improvement, Maternal and Child Health Branch.

## Childhood Lead Poisoning Prevention Case Management System (CLPPP)

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**State Web Site:**

Currently under development

**National Web Site:**

<http://www.cdc.gov/nceh/lead/lead.htm>

### Sources of Information for the CLPPP

Kyran is the KY Child Lead Poisoning Prevention Program (CLPPP)'s case management system. Blood lead tests are administered in local health departments, private physicians' offices and hospitals throughout the state as part of the Lead Poisoning Prevention Program and other health and child related assistance programs. The majority of local health departments and physicians offices do not have the capability to analyze blood samples for lead in house and therefore must contract this service with outside laboratories. These laboratories receive, analyze, and then report the results of such blood samples directly to the health departments and CLPPP. Approximately 99% of laboratories are reporting data electronically to the CLPPP for case management and surveillance purposes.

### Description of Data Collected

Kyran collects data including, but not limited to, the following: patient name, full address, date of birth, phone number, guardian's name, relation and occupation, blood lead test results, blood lead test type (venous or capillary), sample date taken, received by testing lab, reported by testing lab, received by CLPPP, provider and insurance information and demographic information including race, ethnicity, and language.

### Data Set Availability

The fully identified data sets are not available to the public. The CLPPP case manager can be contacted if specific data needs are identified and the sharing of the data would be HIPPA compliant. Tables and reports will be made available on the CLPPP website by 2006.

## Data Publications

The CLPPP currently reports both adult and child blood lead data to NIOSH (<http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5326a2.htm>) and the CDC respectively in the form of quarterly and annual data submissions. The CDC website provides statistical information for the state of Kentucky based on the reports it receives from the state CLPPP. <http://www2.cdc.gov/nceh/lead/census90/house11/house11.htm>. Additional reports and data submissions will become available on-line as the KY CLPPP website is developed. Estimated time of completion is by 2006.

## Data Limitations

Data limitations can fall in to two main categories:

### 1. Incompleteness of data:

Data submitted lacks information necessary for analysis. Names, addresses and date of birth for example are absolutely necessary for entry into the system. Patient records with incorrect data are entered as is and can cause duplication within the system. There is a lack of testing and reporting despite federal and state mandates. As a result, the reported screening numbers are subject to a non-coverage bias.

2. No analysis capabilities: Data must be extracted out of Kyran and placed into a capable program such as Access or SAS in order to perform any type of query. This causes the data analyzed to be a picture of the data on the specific download date and not on a real time basis.

## Specific Uses of Information

The state CLPPP utilizes the Kyran data in the following ways:

- Case manager insures through various means of contact with the local health departments that follow-up care to elevated blood level cases is performed in a timely manner
- History of a case may be viewed
- The completion of annual reports and performance evaluations

Others use the data for:

- Monitor *Healthy Kentuckians 2010* goals
- Estimating the population of lead poisoned children in the state of Kentucky
- Estimating a populations risk of lead poisoning based on their specific demographic and address information
- The CDC utilizes the data to assemble a national surveillance database.

### Strengths of the Data

Data is received in a timely manner and that allows for accurate reporting. With current data submission nearing 100% there is very little manual data entry. Louisville-Metro and Lexington-Fayette Health Departments import large amounts of data directly into the Kyran system in a seamless and efficient manner. The current system is population-based rather than relying on a sampling strategy.

### **System Evaluation**

The data collected are based on CDC and NIOSH guidelines. The data are subject to computerized edit checks when entered.

### **Suggested Data Citation**

None at this time.



## Children's Oral Health Surveillance System (COHSS)

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### Sources of Information for the COHSS

Data are collected annually by dental health professionals who visually screen a sample of Kentucky school children in the 3<sup>rd</sup> and 9<sup>th</sup> grades. During the screening, body mass index (BMI) will also be determined for all participating children.

### Description of Data Collected

The project includes surveillance of 3<sup>rd</sup> and 9<sup>th</sup> grade Kentucky public education students. The sampling is designed as a cumulative replicate sampling over three years. Each sample in each year will be a representative sample of the state 3<sup>rd</sup> and 9<sup>th</sup> grade children, but will also allow for merging as a cumulative sample over the three years, allowing for more precise estimation overall, and for sub-populations. Implicit stratification will be employed by sorting lists of schools containing 3<sup>rd</sup> and 9<sup>th</sup> grade students.

Lists are sorted first by Area Development District (ADD). ADD geographical areas are believed to provide relevant division of the state by geographic, social, and economic factors, and are therefore useful for gaining subpopulation estimates, for describing the state of oral health in the school age population, and for program planning and implementation. The list is further sorted within each ADD to ensure representation by distributing sample selections across other important factors believed to be related to oral health. Depending on the ADD, schools are sorted by urban/rural status, county, and percentage of enrolled students eligible for the free/reduced lunch program.

Lists of data for selection were obtained from the Kentucky Department of Education and are from the 2000-2001 school year. Based on resources available for the surveillance project and enrollment distribution among ADDs, it was determined that 150 schools for 3<sup>rd</sup> grade children and 96 schools for 9<sup>th</sup> grade children could be visited over the three year period of the surveillance project. This requires 50 schools for 3<sup>rd</sup> grade children and 32 schools for 9<sup>th</sup> grade children be visited in each of the 3 replicate years. A slightly higher rate of sampling proportional to population size was

employed in the smallest ADDs to ensure that one school is selected in each of the 15 ADDs in each year of the three year period.

Three replicate samples will be selected from the created and sorted lists. In the second and third years, new data will be evaluated to determine if potential significant shifts in the population require adjustment to the original replicate samples in any of the ADDs. However, the opinion of the investigators is that the population distribution and school enrollments will remain sufficiently stable over a three year period so that modifications to the sampling plan will not be required. Resampling with a similar design could then be completed at three year intervals for future continuation of oral health surveillance of Kentucky school children.

### Data Set Availability

Protocol for data base access has not yet been completed but it is expected that data will be available to research organizations providing that the requestor has signed a confidentiality/security agreement with the Department for Public Health. In some cases, approval by the Cabinet's Institutional Review Board may also be necessary. All data sets will be de-identified with the smallest geographic unit of analysis being the ADD (for specific years). Contact the oral health program data contact for further information on requesting any data sets.

### Data Publications

This surveillance system will begin in Spring of 2005 and analysis will be conducted annually. At present, specific publication times have not been ascertained.

### Data Limitations

The Kentucky Children's Oral Health Surveillance System is a new program beginning in Spring 2005. While only two limitations are listed, additional limitations may be discovered during the implementation of the system.

- Results for each individual year will be weighted to five Kentucky regions. When three years are combined, data will be weighted to the ADD level. The project is unable to collect data weighted to the county level because of the size of many Kentucky county populations.
- No identifying information will be collected for children screened; therefore, data will not be able to be linked to other health records.

### Strengths of the Data

Because this is a visual sample and annual calibrations for screeners are scheduled, the data are expected to be accurate and can be generalized to the total population of Kentucky 3rd and 9th graders. While screening for additional grades (particularly 6th graders) would be desirable, initial years will only include the aforementioned grades.

Because the sample is of sufficient size to be weighted to five Kentucky regions (North, West, Central, East and Jefferson area) annually and to the fifteen ADDs in every third year, the resulting information should recognize sub-populations of the state not previously examined.

Additionally, the collection of BMI information will provide agency health professionals with a statistically accurate sample of under/overweight for Kentucky 3rd and 9th graders.

## Specific Uses of Information

- Provide regional and ADD level children's oral health information for Kentucky children in the 3rd and 9th grades
- Provide regional and ADD level data measuring Kentucky children's BMI status in the 3rd and 9th grades
- Assess carious molars and caries experience, quadrants needing treatment and treatment urgency
- Assess prevalence of dental sealants
- Assess gingival signs
- Dental access and insurance information collected through opt-in parent questionnaire

## System Evaluation

The Children's Oral Health Surveillance System will be an on-going system maintained through a partnership with the University of Kentucky College of Dentistry and the Department for Public Health.

Participating screeners will attend annual calibration training and data collection will be systematically verified by the program administrator who will visually screen a sample of children following the initial screening to assure data consistency.

At the field level, data will be entered into PDA's, which will be downloaded after each visit into a secure server at the University of Kentucky College of Dentistry. Here, data will be evaluated and analyzed.

## Suggested Data Citation

Kentucky Department for Public Health and the University of Kentucky College of Dentistry, *Kentucky Children's Oral Health Surveillance System*, Frankfort, Kentucky: Cabinet for Health and Family Services [data year].

## **Crash Outcome Data Evaluation System (CODES)**

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**State Web Site:** <http://www.kiprc.uky.edu/projects/codes/index.htm>  
**National Web Site:** <http://www-nrd.nhtsa.dot.gov/departments/nrd-30/ncsa/codes.html>

### **Sources of Information for the CODES**

The Crash Outcome Data Evaluation System (CODES) is funded by the National Highway Safety Administration (NHTSA) for the purpose of linking state motor vehicle traffic crash report databases to administratively unrelated databases containing medical and economic information pertaining to persons involved in crashes. At the center of this effort is the Kentucky motor vehicle traffic crash reporting system, called Collision Reporting and Analysis for Safer Highways (CRASH). To date we have linked CRASH with the state inpatient hospital discharge database (HDD). The linkage is accomplished using a probabilistic methodology based upon research by Fellegi and Sunter (1969) and Jaro (1985, 1995), and implemented in software provided by NHTSA. This linked database enables us to discover relationships between crash characteristics and injury outcomes for persons hospitalized as a result of motor vehicle crashes, and to assess the inpatient acute care charges associated with their treatment.

### **Description of Data Collected**

CRASH reports are mandated in Kentucky for crashes occurring on public roadways involving an injury or property damage in the amount of \$500 or more. Officers collect information on all persons involved in the crash, including data on individuals (age, gender, date of birth, seating position, safety belt and helmet use, human contributing factors, and more); vehicles (type, make, model, Vehicle Information Number, extent of damage, vehicular contributing factors, and more); crash event (date, time, and location of crash, manner of collision, first and second collision events, most harmful event, and more); and environment (weather, light conditions, roadway conditions and characteristics, environmental contributing factors, and more).

Hospital discharge reports are mandatory for all discharges of inpatients from hospitals operating in Kentucky. The HDD database includes personal and medical information for each patient, including demographics, diagnosis and procedure codes, external cause of injury, monetary charges and pay-

## Data Set Availability

A public-use Kentucky CODES dataset is not currently available. Aggregated (tabular) data may be requested by contacting the project coordinator. Requests from researchers for access to the linked database will be referred to the project's data owners and Board of Directors for case-by-case consideration.

## Data Publications

We publish a management report annually on our web site: <http://www.kiprc.uky.edu/projects/codes/CODESmngWWW/CODESmanagement.html>.

## Data Limitations

There are two main limitations to the CODES data:

- **Representativeness:** Some persons who are involved in crashes in Kentucky are hospitalized outside of Kentucky, and some who crash outside of Kentucky are hospitalized in Kentucky. Our data sources do not capture out-of-state events, so such cases will not be represented in our linked database. As a result, it is a significant challenge to determine how well the CODES database represents the population of all persons hospitalized as a result of crashes that occur in Kentucky. A more tractable question is how well it represents the population of persons who both crashed and were hospitalized in Kentucky, since these are the cases covered by our data sources. This question has been the focus of our evaluation efforts (see below).
- **Misclassification:** Some data elements on the CRASH reports are inherently difficult to capture reliably. For example, from comparing the reported seat belt use rate on CRASH with results of observational studies we know that the latter is significantly over-reported. This is because the vast majority of persons involved in crashes are not severely injured. By the time the police arrive on the scene it is usually impossible to know whether such occupants were wearing seat belts, so the officer has to rely on self-reporting. The more severe the injury, the more likely the officer can directly observe belt use.

### Strengths of the Data

The combination of these two population-based data sources through probabilistic linkage yields a data source on persons hospitalized as a result of crashes on Kentucky's roadways that enables analyses that would be impossible using either source alone. Crash reports lack reliable information about the type, severity, cost, and treatment of injuries to crash participants. Hospital discharge data lack information about the many factors and circumstances that led to the crash and influenced its severity, and about the use of safety devices. Using the CODES linked database we can discover relationships between risk and protective factors and medical outcomes.

### Specific Uses of Information

- Fact sheets on motor vehicle traffic safety topics
- Peer-reviewed research on traffic safety and injury prevention
- Data requests from NHTSA and from state and local users

### System Evaluation

Both the CRASH and HDD systems perform computerized edit checks at the time reports are entered. Our evaluation efforts have focused on the predictive value positive (PVP) and sensitivity of the linkage process. We conducted an evaluation of the linked CODES database among persons hospitalized at the University of Kentucky Chandler Medical Center (UKMC). The purpose was to determine the percentage of UKMC patients admitted for motor vehicle crash-related injuries who were matched incorrectly to a crash record. We found this type of error in less than 5% of cases. Our conclusion is that the linkage process has a very high PVP for persons who were hospitalized in Kentucky. A second study will estimate the system sensitivity, that is, the percentage of persons who crashed and were hospitalized in Kentucky but who are not represented in the CODES database. This will be accomplished by reviewing medical records for persons admitted to UKMC with an external cause of injury code indicating involvement in a motor vehicle crash, but whom we were unable to link to a CRASH record with a high degree of certainty.

### Suggested Data Citation

Kentucky Injury Prevention and Research Center (KIPRC). *Crash Outcome Data Evaluation System*. Lexington, Kentucky: University of Kentucky [data year].

### References

Fellegi IP, Sunter AB. *A theory for record linkage*. Journal of the American Statistical Association, 1969; 64(328):1183-1210.

Jaro M. *Advances in record linkage methodology as applied to matching the 1985 census of Tampa, Florida*. Journal of the American Statistical Association, 1989; 84(406):16-21.

Jaro M. *Probabilistic linkage of large public health data files*. Statistics in Medicine, 1995; 14:491-498.

## Environmental Health Management Information System (EHMIS)

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### Sources of Information for the EHMIS

The Environmental Health Management Information System (EHMIS) is a comprehensive system designed to collect data for all the environmental health program areas. The EHMIS consists of seven major components: the Establishment file, Request for Service file, Certification file, Sewage file, Accounts Receivable file, Inspection file, and Data Mart or Warehouse.

The Environmental Program regulates over 76,000 facilities or individuals, provides over 330,000 services, and collects approximately \$10,000,000 in fees. The Environmental Program conducts these activities primarily at the local level. Inspections of facilities occur at restaurants, hotels, on-site sewage plants, boarding homes, and swimming pools. New facilities have been added to the EHMIS, including tattoo studios and ear piercing facilities.

### Description of Data Collected

The data are collected by local and state environmentalists and entered in the system locally. A third tier vendor, Custom Data Processing (CDP) stores the data. CDP is a data warehouse utilized for environmental data. These data are demographic data of establishments, as well as inspection data based on health and safety criteria. Establishment record, inspection results, enforcement actions, billing and accounts receivable, permit issuance, individual certification, request for service, animal bite records, and all non-site specific environmental service activity are the categorical headings for data collection.

A second generation EHMIS is in the planning stages. This system will also collect environmental epidemiology investigation data, and will include an expansion/update of existing data collection programs within the system. It will also allow remote inspections performed in the field by the environmentalists.

### Data Set Availability

Data may be accessed and queried using the Discovery data tool, an Oracle database. Additional data requests are available through CDP.

<b>Average Yearly Sample Size</b>	30,000
<b>Smallest Geographic Level Released</b>	Address level
<b>Data Format</b>	Excel
<b>Cost of Data Set</b>	Free

### Data Limitations

There are three main limitations:

**Record Retention:** Collected since mid 80's but can only go back 3 years.

**Data System:** The present state of the data system is based on archaic infrastructure. This inhibits the ability to make changes to the system to meet today's public health demand and querying capacity outside of CDP.

**Coding:** Coding/definition errors occur across the state along with different coding standards, so not able to compare across states.

### Specific Uses of Information

The data are presently used to evaluate the status of environmentalist workload, fee allocation based on services, failed septic systems, quarantine of food items, animal bites, and complaint investigations.

### Suggested Data Citation

None suggested at this time.

### Strengths of the Data

**Geocoding:** The system has a comprehensive list of restaurants, hotels, motels, and other inspected sites, and includes a location for geocoding.

**Timeliness:** The data are entered on a daily basis and updated to the mainframe on weekly basis.



## HIV/AIDS Surveillance System

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**State Web Site:**

<http://chfs.ky.gov/dph/hivaids.htm>

**National Web Site:**

<http://www.cdc.gov/hiv/dhap.htm>

### Sources of Information for the System

According to state regulation 902 KAR 2:020, Section 7, physicians, hospitals, laboratories, counseling and testing sites, and health professions licensed under KRS chapters 311-314 are required to report HIV and AIDS cases to the Kentucky Department for Public Health. New HIV reporting regulations were adopted on July 15, 2004. The regulations require HIV cases to be reported by name and no longer by a 'Unique Identifier'. Surveillance using the new reporting system has not been conducted long enough to estimate diagnosed HIV prevalence; therefore, HIV surveillance data are currently unavailable to the public.

### Description of Data Collected

HIV/AIDS data available to the public include demographic information including race/ethnicity, gender, age at diagnosis, county of residence/area development district (ADD), risk factors of infection, and date of report for adults/adolescents and pediatric cases.

### Data Set Availability

Kentucky HIV/AIDS raw data are not available for public use although data requests/reports can be filled at the public's request with restrictions. For HIV/AIDS semi-annual reports, please use the HIV/AIDS website as listed above. For all other requests, please contact Cheri Holmes at [cherin.holmes@ky.gov](mailto:cherin.holmes@ky.gov) or (502) 564-6539 ext. 3555.

## HIV/AIDS

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### Data Publications

The HIV/AIDS program produces a semi-annual data report by demographic variables and Area Development Districts (ADD). The HIV/AIDS website contains copies of HIV/AIDS statistical reports for the past three years as well as list information on HIV prevention:

<http://chfs.ky.gov/dph/hivaids.htm>.

### Data Limitations

There is a limitation, however, to using the year of diagnosis in analyzing data. As a result of reporting delays, case numbers for the most recent years of diagnosis may not be complete and therefore the most recent years of 2003 and 2004 are not being used in trend analysis data. AIDS data provided by the Kentucky Department for Public Health have not been adjusted for reporting delay.

Another limitation is the lack of HIV prevalence data. Although Kentucky has implemented the name-based reporting system as of July 15, 2004, the recent implementation of this reporting system prevents any HIV data from being released at this time. Therefore, previous HIV prevalence estimates will be adjusted using an adjustment factor based on the change in AIDS prevalence. This adjustment factor was then multiplied by the diagnosed HIV prevalence estimate at the end of 2002 to obtain an estimate of diagnosed HIV prevalence at the end of December 2003.

Lastly, a limitation of the AIDS data includes the number of cases reported with undetermined mode of exposure information. Cases with undetermined mode of exposure can make comparison by mode of exposure difficult. Enhanced surveillance activities have been implemented to attempt to resolve case reports with missing risk factor information.

### Strengths of the Data

The HIV/AIDS surveillance system provides data by age groups, gender, risks, ADD, and by county. The data availability are very timely.

### Specific Uses of Information

- Provides a general and detailed look at Kentucky AIDS cases reported to the Department for Public Health
- Provides data to create and evaluate prevention efforts and service initiatives for HIV/AIDS prevention specialists and community planning groups
- Provides data for grant applications for HIV/AIDS prevention and services
- To identify target populations that are disproportionately affected by HIV/AIDS

### System Evaluation

The data collection is routinely monitored utilizing quality control standards developed by CDC. Chart reviews are conducted on a monthly basis and data reports are run on a quarterly basis and verified through this system.

### **Suggested Data Citation**

Kentucky Department for Public Health (KDPH) and Centers for Disease Control and Prevention (CDC). *HIV/AIDS Surveillance*. Frankfort, Kentucky: Cabinet for Family and Health Services, Kentucky Department for Public Health, [survey year].

## Hospital Inpatient Discharge Database

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**State Web Site:**

[Under Construction](#)

**National Web Site:**

<http://www.ahrq.gov/hcupnet/>

### Sources of Information for the Database

The Kentucky Hospital Inpatient Discharge Database is a collection of records each of which describes a single inpatient stay in a Kentucky hospital. These data are collected under the requirements set forth in KRS 216.2920-216.2947 as the basis for regular reporting of cost, quality, and outcomes measures relative to hospital inpatient events. Actual data collection, verification, and storage is performed on a quarterly basis by an external contractor through a cooperative agreement with the Cabinet for Health and Family Services and the Kentucky Hospital Association (KHA). The Cabinet and KHA have collaborated in this effort since 2000.

### Description of Data Collected

Each record in a hospital discharge data set includes demographic fields (gender, age group, state, county, and ZIP code of residence), a unique hospital identifier, hospital stay fields (admission type and source, length of stay, diagnoses codes, procedure codes, discharge status, and total charges), and grouping codes (Major Diagnostic Category, Diagnosis Related Group). Personal identifying information, such as name, address, and social security number, and race/ethnicity is not included in these data.

# Hospital Inpatient Discharge Database

## Data Set Availability

Kentucky inpatient hospitalization data from 2000 to the present are available to the public in yearly data sets. Data files are formatted as fixed-field fixed-length ASCII records and come with translation tables for coded data. Data users are required to sign a Data Users' Agreement (see Appendix E) before data files are transferred. Files containing the previous calendar year's data are available each July.

<b>Average Yearly File Size:</b>	650,000 records of 156 bytes each
<b>Hospital Compliance Rate:</b>	>99%
<b>Smallest Geographic Level Released:</b>	ZIP
<b>Data Format:</b>	ASCII, fixed-length fields
<b>Cost of Data Set:</b>	\$1,500 per yearly file
<b>Other requirements:</b>	Signed Data User's Agreement

## Data Publications

Kentucky inpatient hospitalization data are regularly summarized and published as a part of the annual Hospital Utilization Survey (Leading Twenty-five DRGs by Area Development District of Hospital). The data are also included in annual reports for programs in the Chronic Disease Prevention and Control Branch (e.g. asthma, diabetes, cardiovascular health, etc).

## Data Limitations

The records comprising these data files are built from hospital-submitted claims to payers, commonly known as UB 92 records. These files contain all inpatient discharges from a given calendar year, these are claims data and must be used with caution in epidemiological analysis. Furthermore, individual records represent single admit-through-discharge events; multiple admissions of an individual patient cannot be definitively identified. For this reason, these data should not be used to directly measure the prevalence of a condition in the general population.

## Strengths of the Data

The included data items are sufficient to allow detailed demographic, diagnostic, and outcome analysis for public health reporting and research. These data are valuable in preparing chronic disease burden documents, grant proposals and justifications, resource utilization reports, and ad hoc studies of the health status of Kentuckians. The spatial components of these data can be exploited to illustrate regional hospitalization patterns and trends related to conditions such as influenza, asthma, and diabetes and to show regional variation in hospital coverage and services. These data are also included in the National Inpatient Sample (NIS), a combined sample from hospitals in more than thirty states covering inpatient events in over 90% of U.S. hospitals.

## Hospital Inpatient Discharge Database

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### Specific Uses of Information

- Inpatient and outpatient hospitalization data are submitted annually to the Agency for Healthcare Research and Quality's Health Care Utilization Project (H-CUP) for inclusion in the National Inpatient Sample
- A subset of the hospitalization database plays a critical role in populating the Kentucky Birth Surveillance Registry
- Hospitalization data are used in preparing grant requests and status reports for Kentucky Department for Public Health programs in asthma, cardiovascular disease, diabetes, and maternal and child health
- Hospitalization data provide information for evaluating the improvement of health of the citizens of the Commonwealth as detailed in Healthy Kentuckians 2010
- Summaries of hospitalization data are instrumental in developing and implementing Kentucky health care policies and decisions at the state level
- Hospitalization data are frequently requested by public health researchers, educators, and consultants for a variety of individual projects

### System Evaluation

Data is verified as it is submitted, undergoing checks for presence and completeness of required fields, validity of submitted items, duplicate record checks, and timeliness. Records with errors or omissions are returned to submitting hospitals for correction and resubmission.

### Suggested Data Citation

Kentucky Inpatient Hospitalization Claims Files, Frankfort, KY, [year(s)]; Cabinet for Health and Family Services, Kentucky Department for Public Health, Health Policy Analysis Branch.

## Influenza Sentinel Surveillance System (ISSS)

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<b>State Web Site:</b>	<a href="http://chfs.ky.gov/dph">http://chfs.ky.gov/dph</a> Laboratory Confirmed Cases Only Chart
<b>National Web Site:</b>	<a href="http://cdc.gov/flu/weekly/fluactivity.htm">http://cdc.gov/flu/weekly/fluactivity.htm</a> National Influenza Activity

### Sources of Information for the ISSS

Influenza like illness (ILI) is reported by sentinel Local Health Department (LHD) sites. All sites surveil absenteeism in a school district, or schools representative of grades K-12, for one day each week. Every site is requested to also surveil a nursing home for ILI. Some LHD sites also surveil health care providers and hospitals.

Sentinel Health Care Provider (HCP) sites report ILI to the Centers for Disease Control and Prevention (CDC), and obtain specimens for laboratory culture confirmation.

Mandatory reporting of culture confirmed cases within one week is required of laboratories.

Long-term care facilities are required by law to report immediately to the LHD, two or more ILI within a one-week period of time.

### Description of Data Collected

Beginning October through May, LHD sentinel sites send an email, fax or phone in weekly reports of (ILI) counts received from medical practices, nursing homes and hospitals; absenteeism for schools is collected on Tuesdays. Numbers and types of influenza virus isolates from clinical laboratories are maintained in a database and reported to CDC. Rapid diagnostic positive test results are received passively, and are kept in a separate database for the state's information only. HCP sentinel sites

send information about ILI by age group to CDC through an automated touch-tone system, fax or phone. The state influenza coordinator has access to the computer data. Laboratory confirmed cases, ILI reports from sentinel LHD sites and HCP sentinel sites are considered in determining the state's activity code for each week. The state's activity code is reported to the CDC. The information is, also, compared to previous weeks of the current season and to previous influenza seasons.

ILI and absentees for six weeks in the fall are used to determine outbreak baseline numbers for LHD sentinel site participants. HCPs and hospital outbreak baseline numbers are three ILI. The nursing home outbreak baseline number is two. School absentees for six weeks are added together, divided by six and multiplied by two to obtain an outbreak baseline number for each participating school district. Outbreak baseline numbers are used to compare the levels of ILI. The state influenza coordinator uses all the information to make a subjective determination regarding the influenza activity rating for the State Epidemiologist's report each week. Activity levels and definitions are:

- No Activity-Overall clinical activity remains low and there are no lab confirmed cases;
- Sporadic-Isolated cases of lab confirmed influenza in the state and ILI activity is not increased, or lab confirmed outbreak in a single institution in the state and ILI activity is not increased;
- Local outbreak-Increased ILI within a single region and recent (within the past three weeks) laboratory evidence of influenza in that region. ILI activity in other regions is not increased, or two or more institutional outbreaks (ILI or lab confirmed) within a single region AND recent lab confirmed influenza in that region. Other regions do not have increased ILI and virus activity is no greater than sporadic in those regions;
- Regional-Increased ILI in greater than or equal to two but less than half of the regions AND recent lab confirmed influenza in the affected regions, or institutional outbreaks (ILI or lab confirmed) in greater than or equal to two and less than half of the regions AND recent lab confirmed influenza in the affected regions;
- Widespread-Increased ILI and/or institutional outbreaks (ILI or lab confirmed) in at least half of the regions AND recent lab confirmed influenza in the state.
  - ◇ Lab confirmed case=case confirmed by rapid diagnostic test, antigen detection, culture, or PCR. (At the beginning of the season, the State Epidemiologist may report No Activity until there is evidence of culture confirmed cases in the state, regardless of rapid antigen reports.)
  - ◇ Institution includes nursing home, hospital, prison, school, etc. ILI activity can be assessed using a variety of data sources including sentinel providers, school/workplace absenteeism, and other syndromic surveillance systems that monitor influenza-like illness.
  - ◇ Region-Geographical subdivision of a state defined by the DOH (department of health). (In KY, the 15 Area Development Districts are used.) The identity of specific isolates from Kentucky and other nearby states, and information on the age of the person tested and date of collection of the isolate, are used to interpret whether outbreaks of influenza-like illness in the state actually represent influenza, and if so, what type and whether the strain is thought to be a close match to the content of the currently available vaccine.



## Data Set Availability

Only the cumulative laboratory information by county is available on the department website.

## Data Publications

Data publications include *Kentucky Epidemiologic Notes and Reports* seasonal summary, weekly influenza laboratory confirmed cases charts on the website, *Yearly Reportable Disease Summary*, and the *Five-year Summary for Reportable Diseases*.

## Data Limitations

The system relies on the accuracy of reporting by the sentinel sites.

## Specific Uses of Information

The activity information can be used to promote influenza immunization, let clinicians know whether the circulating strain is a match for the current vaccine; and whether it is one which will respond to antiviral chemoprophylaxis and therapy. In addition, laboratory information can be used to prepare for the possibility of responding to an influenza pandemic. The public can be informed about what influenza strain is circulating, how influenza activity compares with other years, and what populations are affected. The state influenza coordinator sends a weekly activity report to the Cabinet's Communications Office and the CHR Infection Control list serve for release to the media.

### Strengths of the Data

The current system has done an excellent job of profiling the influenza activity at the end of each season, comparing its severity and pattern to other seasons, and in identifying the virus or viruses responsible for most of the activity for that season. The system complements that of other states and provides valuable input to the process of selecting strains for the following year's vaccine, and to the strategy for annual vaccination campaigns.

## System Evaluation

The system is informally evaluated at the end of each influenza season. Summary information is evaluated by the State Influenza Coordinator, and the coordinator determines how well the system provided answers to the frequently asked questions during the season. The system has not been formally evaluated.

## Suggested Data Citation

Kentucky Department for Public Health (KDPH). Diseases and Conditions. Frankfort, Kentucky: Cabinet for Health and Family Services.

## Kentucky Birth Surveillance Registry (KBSR)

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**State Web Site:**

<http://chfs.ky.gov/dph/ach/kbsr.htm>

**National Web Site:**

<http://www.nbdpn.org/index.html>

### Sources of Information for the KBSR

The Kentucky Birth Surveillance Registry (KBSR) is a state mandated surveillance system that is co-sponsored by the Centers for Disease Control and Prevention (CDC) and the Kentucky Department for Public Health. The system is designed to provide information on incidence, prevalence, trends and possible causes of stillbirths, birth defects and disabling conditions. The KBSR operates under the authority of KRS 211.651-670 and is located organizationally in the Cabinet for Health and Family Services, Department for Public Health, Division of Adult and Child Health Improvement, Maternal and Child Health Branch.

### Description of Data Collected

The KBSR collects information from vital records, acute care, and birthing hospitals, laboratory reporting, and voluntary outpatient reporting on all children from birth to five years of age who are diagnosed with any structural, functional, or biochemical abnormality determined genetically or induced during gestation. Newborn nursery, NICU, and labor/delivery logbooks are reviewed on a monthly basis in participating hospitals with the largest number of births. Medical records of the child are reviewed on a monthly basis to verify a physician diagnosis of major structural anomalies. Hospital discharge data and laboratory reporting are received on a quarterly basis, and the information is prepared for medical record abstraction. Vital records including live births and deaths are reported to KBSR on a monthly basis with stillbirths being reviewed on a weekly basis. Personal identifying information as well as diagnostic codes are collected by KBSR, and it is therefore considered a highly confidential database. Due to the sensitive nature of the data and laws designed to protect the individual, no personal identifying information is released from KBSR and data is only presented

or released in aggregate fashion. The lowest demographic level of information that can be provided by KBSR is the Area Development District (ADD) level; county level data are not available.

## Data Set Availability

KBSR data from 1998 to present are available to certain individuals provided an institutional review board (IRB) approval to access the data has been obtained. KBSR staff reserve the right to deny any data request they deem would violate state and or federal laws governing the data set. The data set is only available in aggregate form and NO identifying information will be released to any requestor under any circumstances. National data are available on the National Birth Defects Prevention Network web site.

## Data Publications

The KBSR produces an annual report that contains trend data on certain conditions collected by the registry. The data are broken out by sex, race, and maternal age and when applicable by ADD. <http://chfs.ky.gov/dph/kbsr> A separate report on Neural Tube Defects is produced annually and also contains trend data broken out by sex, race, and maternal age and ADD. KBSR also participates in the annual report on birth defect surveillance systems published in *Birth Defects Research*, which includes a basic description of the surveillance system and data for five years broken out by race, and for chromosome disorders by maternal age.

## Data Limitations

There is one main limitation to KBSR data; small numbers when dealing with individual defects. As a result, data must be presented in an aggregate fashion and cannot be provided by county level. Also, the sensitive nature of the data plays a role in what can and cannot be released to data requestors. This limitation should not hinder the use of KBSR data but should be considered.

Two other limitations that KBSR is working to correct include: capturing out-of-state births to Kentucky resident mothers, not all cases are being captured in KBSR, and currently KBSR does not collect prenatally diagnosed cases of birth defects that are lost prior to 20 weeks gestation.

### Strengths of the Data

The KBSR provides data on certain birth defects, genetic and disabling conditions, pregnancy outcomes and maternal risk factors that are not collected by other surveillance systems. The KBSR is a statewide mandated system, therefore, reporting entities are required by law to provide the data as described under KRS 211.651-670. Data are readily accessible only by three full-time staff members in the MCH branch and are updated on a monthly basis. Data provided to KBSR occurs in a timely fashion with all birthing hospitals in the state currently submitting data through a vendor on a quarterly basis. Medical records abstraction is consistently conducted on a monthly schedule and data from 1998-third quarter 2004 have been verified.

## **Specific Uses of Information**

- Monitor *Healthy Kentuckians 2010 Goals*
- Monitor KIDS NOW Initiatives on Early Childhood Development
- Provide data for use in various projects by the Folic Acid Partnership of KY, the March of Dimes KY chapter, the Spina Bifida Association of KY, and the National Birth Defects Prevention Network
- Data on specific abnormalities are currently being used for a National Birth Defects study
- Data provided for the World Health Organization Craniofacial Study
- Data provided on specific birth defects for the Environmental Quality Commission report, "Children's Health"
- Data are used annually for the preparation of the grant application "Cooperative Agreements for the Development and Improvement of Population-Based Birth Defects Surveillance Programs"
- Data are used annually to monitor trends of birth defects among specific populations, geographical areas, and the state as a whole and to monitor any cluster outbreaks and to evaluate health disparities

## **System Evaluation**

Data collection for KBSR is monitored closely with a quarterly analysis of timeliness (number of days from birth to import into the system) and uniqueness of reporting sources. In addition, with each quarterly submission of hospital discharge data, 23 analyses are completed for omissions, errors, and completeness of records. Those records found to have omissions, errors or incomplete information are returned to the vendor for correction. KBSR also monitors the number of UB92 records submitted by each hospital by quarter to identify any changes. A report is also generated quarterly in terms of the total number of records abstracted to date and the total number of records received each quarter into the database. A proportion of the cases within KBSR are being re-abstracted to establish an error rate from the medical records abstraction component, and an annual comparison of the percentage of Kentucky residents reported with birth defects to national numbers is made.

## **Suggested Data Citation**

*Kentucky Birth Surveillance Registry Data, (Year)*; Kentucky Department for Public Health, Division of Adult and Child Health Improvement, Maternal and Child Health Branch.

## Kentucky Cancer Registry (KCR)

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**State Web Site:**

[www.kcr.uky.edu](http://www.kcr.uky.edu)

### Sources of Information for the KCR

All licensed healthcare facilities in Kentucky are required by state law to report all cancer cases diagnosed and/or treated in those facilities to the Kentucky Cancer Registry (KCR). Thus, KCR collects data from hospitals, outpatient facilities, freestanding diagnosis and treatment facilities, pathology laboratories, multi-specialty clinics, and doctors' offices. In addition, reciprocal data exchange agreements allow KCR to obtain information on Kentucky residents with cancer who are seen or treated in contiguous states. Finally, KCR links registry data with the Kentucky death certificates, in order to identify any cancer diagnoses made upon death which were not previously reported to the registry.

### Description of Data Collected

Cancer information collected includes primary site and cell type of cancer, as well as date and stage of disease at diagnosis. Follow up information includes vital status at date of last contact, and date and cause of death, when applicable. Patient demographic information is also collected including address, race, sex, Spanish ethnicity, and date of birth.

### Data Set Availability

Due to the sensitive nature of the data and laws designed to protect the individual, the fully identified cancer case records are subject to a strict confidentiality policy. They are NOT available to the public. Data sets may be made available to qualified researchers who have submitted a written application to KCR and have been approved by an internal review panel. In some cases, approval from the institution's Internal Review Board may be required as well. Contact the KCR Research Coordinator for further information on requesting any data sets.

### Data Publications

The Kentucky Cancer Registry publishes the *Kentucky Cancer Incidence Report* annually. Starting with 1995, most tables in the report can be found on the Kentucky cancer registry web site: [www.kcr.uky.edu](http://www.kcr.uky.edu).

### Data Limitations

There are two main limitations to the cancer registry data:

- Incompleteness of treatment data: Patients are often treated with multi-modality therapy in a wide variety of settings over a long period of time. Due to the confidential nature of the data being collected, it is often difficult to capture complete information on all treatments received.
- Timeliness: Hospitals are allowed six months from the date of initial contact with a patient before the cancer report is required to be sent to KCR. This is necessary in order to allow time for collection of complete or nearly complete records. Time is then spent to obtain out-of-state and death certificate records and complete a final edit of the data. There is currently a delay of two years in establishing a "complete" annual database. Finally, in order to produce the cancer rates for the numerous tables in the annual *Kentucky Cancer Incidence Report*, KCR must rely on other agencies for population estimates, which also contributes to the delay in data availability.

### Strengths of the Data

The cancer registry is population-based, rather than relying on a sampling strategy. Electronic data have been maintained in a consistent format since 1991. Collection protocols and formats follow national standards set by the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program, the American College of Surgeons' Commission on Cancer, and the North American Association of Central Cancer Registries (NAACCR). Data from KCR have been submitted to NAACCR for an objective evaluation of completeness, accuracy and timeliness each year since the certification program was established. In each year (1995 through 2002) KCR has received the highest level of NAACCR certification available (Gold certification).

## Specific Uses of Information

- Provide data used to calculate cancer incidence by age, race, gender, and place of residence
- Provide cancer incidence statistics for a variety of purposes and programs of state government for cancer prevention and control efforts
- Provide data to assess the cancer burden in Kentucky, by both government agencies and other healthcare researchers
- Provide data to the National Cancer Institute, the Centers for Disease Control and Prevention, and the North American Association of Central Cancer Registries for estimating the cancer burden in the United States

## System Evaluation

The data are subject to computerized edit checks when entered. Corrections and amendments are made to the database on an on-going basis. The KCR data are also subjected to annual external audits and evaluations and have been deemed to be of high quality.

## Suggested Data Citation

Kentucky Cancer Registry. *[dates covered] Cancer Incidence Report*. Lexington (KY): University of Kentucky, Markey Cancer Control Program; [date published].

Example:

Kentucky Cancer Registry. *1998-2002 Cancer Incidence Report*. Lexington (KY): University of Kentucky, Markey Cancer Control Program; 2005.

## Suggested Web Citation

Kentucky Cancer Registry. ([date updated]). *Cancer Incidence/Mortality Rates in Kentucky*. Retrieved [date] from <http://www.kcr.uky.edu/>

Example:

Kentucky Cancer Registry. (2005). *Cancer Incidence Rates in Kentucky*. Retrieved February 16, 2005 from <http://www.kcr.uky.edu/>

## Kentucky Incentives for Prevention (KIP) Student Survey

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**Data Contact:**

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### Sources of Information for the KIP

The Kentucky Incentives for Prevention (KIP) student survey is a classroom administered health survey sponsored by the Substance Abuse Prevention Program (SAPP) in the Kentucky Department for Mental Health and Mental Retardation, through agreements with individual school districts across the state. The survey is now conducted bi-annually in the fall of even-numbered years (2004, 2006, etc), with 6th, 8th, 10th, and 12th graders attending school in Kentucky communities. The participation of school districts and individual students in the survey is voluntary and student personal identifying information, such as name or address, is not collected.

### Description of Data Collected

The KIP survey collects data on student use of alcohol, tobacco, and other drugs (ATOD), as well as a number of factors related to potential substance abuse, including peer influences, perception of risk, family factors, and school safety. Demographic data collected include age, grade level, gender, race, ethnicity, and urban/rural residence. The core items on the present KIP survey were originally chosen by the federal Center for Substance Abuse Prevention (CSAP), based on extensive research on risk and resilience factors associated with youth substance abuse. Additional items have been added that are specific to Kentucky.

### Data Set Availability

Since KIP survey data are the “property” of the schools, permission of the school district is required in order to access the data at the local level.



## Data Limitations

There are two main limitations to the KIP survey to be considered, but these limitations should not prevent the use of the KIP data.

**Self-report Bias:** The KIP survey relies on self-report. That means that prevalence estimates are based on each student's answers to the questions. The tendency to report healthier behaviors and inaccuracies due to faulty recall of activities may occur.

**Non-Random Sample:** The KIP survey is administered voluntarily to schools and students, and hence does not utilize a random sample. The survey sample covers all regions of the state of Kentucky, but is not a random sample. This limitation should always be considered when using KIP data.

### Strengths of the Data

The KIP survey provides state and school district level data in a timely and user friendly format. KIP survey data provide data from Kentucky that can be compared to other states and national data.

## Specific Uses of Information

- Provide data for government agencies to monitor *Healthy Kentuckians 2010* goals
- Provide data to design and evaluate substance abuse prevention initiatives

## System Evaluation

Questions are assessed annually to determine which ones are appropriate based on reliability testing and factor analysis.

## Suggested Data Citation

Resources for Education, Adaptation, Change, & Health (REACH). *Kentucky Incentives for Prevention Survey Data*. Louisville, KY: REACH, [survey year].

## Kentucky Trauma Registry (KTR)

### Coordinator/ Data Contact

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### Sources of Information for the KTR

The Kentucky Trauma Registry is an initiative of the Kentucky chapter of the American College of Surgeons' (ACOS) Committee on Trauma and the Kentucky Board of Emergency Medical Services. Data are collected by ACS-verified trauma facilities and reported to the Kentucky Injury Prevention & Research Center (KIPRC) at least annually. Data are also collected for Kentucky residents who are treated at Ohio verified trauma facilities and will soon be collected from their counterparts in Tennessee.

### Description of Data Collected

Trauma registry data include hospital name, patient gender, sex, birthday, race, county of injury and residence, zip code, date and time of injury, arrival, and discharge, referring hospital, E-code, Injury Severity Score (ISS), Glasgow Coma Score (GCS), trauma score, Revised Probability of Survival (RPS), Blood Alcohol Level (ETOH), ICD-9 codes, length of stay, number of ICU days, and disposition.

### Data Set Availability

Kentucky Trauma Registry data are not generally available. Requests for data access should be addressed to Mr. Napier at KIPRC.

### Data Publications

The second Kentucky Trauma Registry report was published in December 2004 and is available from the Kentucky Injury Prevention and Research Center.

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## Data Limitations

There are two important limitations that keep the trauma registry from achieving its full potential. The first is variation in inclusion criteria across facilities. Notably, the University of Louisville Hospital does not include data for hospitalizations of less than 48 hours unless the patient expires at the hospital. Thus, data from the two Level I trauma centers at the University of Kentucky and University of Louisville Hospitals cannot be aggregated or compared meaningfully. The second limitation is that the trauma registry only includes data from facilities that are either ACOS-verified or self-designated trauma centers. It is clear that serious trauma is also cared for at many other general acute care facilities across the state that do not elect to pursue ACOS-verified status. The trauma registry therefore does not provide as complete an account of traumatic injury in Kentucky as might be the case were reporting spread across a larger group of facilities.

## Specific Uses of Information

Trauma registry data are used for trauma system planning, informing legislative initiatives, and identification of areas in which additional activity is necessary.

## Suggested Data Citation

Kentucky Trauma Registry 1995-2002, Kentucky Injury Prevention and Research Center. Lexington, KY: December 2004.

### Strengths of the Data

The Kentucky Trauma Registry provides a rich database regarding Kentuckians who incur serious traumatic injury that is cared for in the state's verified facilities. It supports the identification of areas in which the state deviates from national norms regarding traumatic injury incidence, characteristics, and care.

## Kentucky Women's Cancer Screening Program (KWCSF)

**Coordinator:**

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**State Web Site:**

<http://chfs.ky.gov/dph/ach/cancerscreening.htm>

**National Web Site:**

<http://www.cdc.gov/cancer/nbccedp/>

### Sources of Information for the KWCSF

Kentucky Women's Cancer Screening Program (KWCSF) collects surveillance data from all the 120 local health departments on women served through the program and semiannually reports to the Centers for Disease Control and Prevention (CDC) a set of standardized data elements called Minimum Data Elements (MDE) to describe basic demographic characteristics, screening history, and screening and diagnostic outcomes for these women. The KWCSF has collected MDE's continuously since 1998 and is located organizationally in the Cabinet for Health and Family Services, Department for Public Health, Division of Adult and Child Health Improvement, Maternal and Child Health Branch.

### Description of Data Collected

The Minimum Data Elements (MDE's) are a set of standardized data variables developed to ensure that consistent and complete information on screening location, patient demographic characteristics, screening results, diagnostic procedures, final diagnosis, and treatment information is collected on women screened or diagnosed with National Breast and Cervical Cancer Early Detection Program funds. The MDE's are divided into three sections: the All Patients Section, the Abnormal Pap test Section, and the Abnormal Mammogram/Clinical Breast Exam (CBE) Section. The All Patients Section is completed for each screening test performed for women with program funds. It includes the screening location, patient demographic information, and screening results for Pap tests, mammograms, and clinical breast exams. The Abnormal Pap Test Section and the Abnormal Mammogram/CBE Section are completed only for abnormal Pap test results and abnormal mammogram/CBE screening results. These sections provide data on diagnostic procedures, final diagnoses, and treatment for breast and cervical cancer.

## Data Set Availability

KWCSPP's MDE's are not yet available to the public; however yearly statewide summaries of breast cancers are available to public. Efforts are underway to provide this information by the end of October 2005 to the public. Data sets can be provided before October 2005 upon request. The statewide data are available in both SPSS and Text formats. National data are available on the national web site: <http://www.cdc.gov/cancer/nbcedp/sps/index.htm>.

<b>Average Yearly Sample Size</b>	11,000
<b>Smallest Geographic Level Released</b>	County
<b>Data Format</b>	SPSS, Text format
<b>Cost of Data Set</b>	Free

## Data Publications

The KWCSPP program produces a yearly statewide summary of breast cancers by demographic variables and Area Development District (ADD). National reports can be found at <http://www.cdc.gov/cancer/nbcedp/Reports/NationalReport/index.htm>

## Data Limitations

Data are available only for women ages 40-64, below 250% poverty level and not eligible for Medicare, Medicaid, and have no private insurance.

## Specific Uses of Information

- Breast and cervical cancer screening participation
- Breast and cervical cancer screening results
- Breast and cervical cancer screening diagnostic follow-up
- Breast and cervical cancer detection and diagnosis
- Stage of invasive breast and cervical cancer at time of diagnosis
- To evaluate health disparities

## System Evaluation

The data collection is routinely monitored utilizing quality control standards developed by CDC.

## Suggested Data Citation

Kentucky Department for Public Health (KDPH) and Centers for Disease Control and Prevention (CDC). Kentucky Women's Cancer Screening MDE Data. Frankfort, Kentucky: Cabinet for Health and Family Services, Kentucky Department for Public Health, [Screening Period].

### Strengths of the Data

The MDE's are accurate, complete and timely and are used to establish KWCSPP policies and practices, assess the KY state program's screening outcomes, and respond to the information needs of CDC stakeholders and partners. The data at present are 98.2% complete. Screening data are available after 3.5 months and diagnostic data are available 9 1/2 months from the cut off date, which is June 30 and Dec 31<sup>st</sup> of every year. MDEs are collected from all 50 states, 4 U.S. territories, the District of Columbia, and 13 American Indian/Alaska Native tribes or organizations; therefore, data from Kentucky may be compared to other states.

## **Perinatal Hepatitis B Screening (Perinatal Hep B)**

**Coordinator/Data Contact:**

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### **Sources of Information for the Screening**

Information in the system is based upon identifying information and demographics on any prenatal patient seen by local health departments and private providers who has a positive hepatitis B surface antigen (HBsAg) screening test, Estimated Date of Confinement (EDC), name of local health department and contact nurse, private doctor's name, and outcome of pregnancy.

### **Description of Data Collected**

Reports of positive HBsAG tests on all prenatal patients are forwarded from the state laboratory (or from the local health department, if test was performed in another clinical laboratory) to the Department for Public Health, Division of Epidemiology and Health Planning. The Immunization Program then obtains the demographic and clinical information from the local health department and enters the patient in a registry. When the infant is born, the health department reports dates of Hepatitis B Immune Globulin (HBIG) and hepatitis B vaccine series receipt and date and result of follow up antibody testing. The Immunization Program follows up monthly for missing reports. Line listings with the above information are forwarded to the Division of Epidemiology and Health Planning, Immunization Program where prevalence of HBsAg, follow-up rates and efficacy of the prevention regimen are calculated. Summary information is disseminated by the Immunization Program, Division of Epidemiology and Health Planning to local health departments, immunization field staff and the Centers for Disease Control and Prevention (CDC).

### **Data Limitations**

Information is limited to those provided by local health departments, primary care physicians and birthing hospitals.

### Specific Uses of Information

- Monitor the prevalence of hepatitis B in the population of delivering mothers who use health department services and private doctors
- Track changes in the overall epidemiology of hepatitis B
- Assure that infants at risk of perinatal transmission receive hepatitis B immune globulin and vaccine to prevent disease
- Monitor for vaccine failures in infants of hepatitis B positive mothers who receive the preventive regimen

### System Evaluation

The system is evaluated annually by way of a report submitted to the CDC. The report enumerates the number of births to HBsAg positive mothers, vaccination completion rates and post-vaccination testing rates.

#### Strengths of the Data

Provides surveillance and monitoring to known cases of children born to Hepatitis B positive mothers.

## Reportable Disease Surveillance System (RDSS)

**Coordinator:**

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**State Web Site:**

<http://chfs.ky.gov/dph>

**National Web Site:**

<http://www.cdc.gov/eпо/dphsi/phs.htm>

### Sources of Information for the RDSS

Information in the system is based on demographic, clinical, laboratory, and risk factor information on each occurrence of any one of sixty-eight reportable diseases. The data are taken from the EPID 200 Reportable Disease Form or the Kentucky Electronic Public Health Records System (KYEPHRS) from selected Centers for Disease Control and Prevention (CDC) disease supplemental forms and clinical laboratory reports. Disease reporting is a required activity by health care providers, hospitals, clinics, and laboratories and is regulated by the State of Kentucky through the Kentucky Disease Surveillance Administrative Regulation 902 KAR 2:020, Disease Surveillance.

### Description of Data Collected

The Reportable Disease Surveillance System (RDSS) collects data on demographics, clinical symptoms, risk factors, and outbreak associations. Demographic data collected include gender, age, race, ethnicity, and place of residence. Information from supplemental forms for some diseases is also entered into the system. This information is sent from hospitals, clinics, local health departments, private practice physicians, and commercial laboratories by mail or by fax. An electronic web version will be utilized after June 2005.

### Data Set Availability

The fully identified data set is not available to the public. Portions of the data set can be shared and identified data can be made available to research organizations providing that the requestor has signed a confidentiality/security agreement with the Department for Public Health. Occasionally approval by the Institutional Review Board is necessary.



## Data Publications

The Reportable Disease program produces a yearly statewide summary. Yearly summaries can be found on the Data Warehouse web site <http://chfs.ky.gov/dph/surv.htm> . Data are also periodically posted on *Epidemiologic Notes and Reports*.

## Data Limitations

There are four main limitations to the reportable disease data:

- Data on the EPID200 form and KYEPHRS are often incomplete. Follow-up is many times difficult and/or unproductive in obtaining the necessary information.
- Data are often sent to the local health department or state weeks and sometimes months after the reportable event. This makes follow-up even more difficult.
- Data are not readily available to all. Data must be transferred to another program such as EpiInfo. Gleaning the data wanted can be cumbersome and is usually done by reportable disease employees. It is then sent out electronically to the requestor.
- Data collection is dependent on health care providers reporting the data to the state.

### Strengths of the Data

One of the strengths of this data should come from the fact that certain diseases are required to be reported to the Department for Public Health by law. However, the level of compliance in the state of Kentucky varies wildly depending on the disease.

## Specific Uses of Information

- Monitor disease trends in the state.
- Provide data to create and evaluate prevention and treatment initiatives.
- Provide data to CDC for national reportable disease statistics.
- Provide data for grant applications related reportable diseases in Kentucky.
- To monitor evaluate geographic and or spatial characteristics of disease.
- To monitor and evaluate outbreaks of disease.

## System Evaluation

The data collection is routinely monitored utilizing quality control standards developed by CDC. Yearly checks are done before the CDC data files are closed.

## Suggested Data Citation

Kentucky Department for Public Health (KDPH) Reportable Disease File. Frankfort, Kentucky. Cabinet for Health and Family Services [data year].

## Vital Statistics Surveillance System (Vital Stats)

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<b>State Web Site:</b>	<a href="http://chfs.ky.gov/dph/vital/vitalstats.htm">http://chfs.ky.gov/dph/vital/vitalstats.htm</a>
<b>National Web Site:</b>	<a href="http://www.cdc.gov/nchs/nvss.htm">http://www.cdc.gov/nchs/nvss.htm</a>

### Sources of Information for the System

Information in the system is based upon birth, death, stillbirth, marriage, and divorce certificates collected and maintained by the Vital Statistics Branch. Almost 99% of birth records are reported electronically from hospitals. The remainder of the birth records, as well as all death, stillbirth, marriage, and divorce certificate data are reported on paper, and are keyed to mainframe data files.

### Description of Data Collected

On births (and stillbirths), the system collects identifying information on the newborn and parents; demographic data such as address, age, race, and Hispanic origin of the parents; mother's previous pregnancy history; circumstances of the birth such as plurality, birth weight, obstetric procedures, and abnormal conditions of the newborn; and medical risk factors such as tobacco and alcohol use during pregnancy (and cause of fetal death in the case of stillbirths). Data are collected on all births that occur in Kentucky or that occur to a Kentucky resident out-of-state.

On deaths, the system collects identifying information on the decedent; demographic data such as address, age, sex, race, and occupation; circumstances of the death such as date and place; the underlying cause of death, and up to three supplemental, or contributing causes. Data are collected on all deaths that occur in Kentucky or that occur to a Kentucky resident out-of-state.

On marriages and divorces, the system collects identifying information on the husband and wife, and the date and county of the event on all marriages and divorces that occur in Kentucky.

### Data Set Availability

The fully identified birth, stillbirth, and death certificate data sets are not available to the public. However, they can be made available to research organizations, at cost, through file transfer protocol (FTP) providing that the requestor has signed a confidentiality/security agreement with the Department for Public Health. In some cases, approval by the Cabinet's Institutional Review Board may also be necessary. De-identified data sets can be made available, the smallest geographic unit of analysis being the county. Contact the vital statistics data contact for further information on requesting any data sets. National data are available on the NCHS web site.

### Data Publications

The Surveillance and Health Data Branch publishes the *Kentucky Annual Vital Statistics Report*. Starting with 1997, most tables in the report can be found on the Kentucky public health web site <http://chfs.ky.gov/dph/vital/vitalstats.htm>.

### Data Limitations

There are three main limitations to the vital statistics data:

- Incompleteness of residence data: Each state registers vital events that occur within its jurisdiction. In order to collect data on vital events that occur to its residents in other states, the state of residence must depend upon the state of occurrence to transmit these records, known as intransfers, back to the state of residence. Even though numerous attempts are made to collect these records, we rarely receive 100% of them from all the other states. Consequently, the total number of records in our files is usually less than nationally published statistics for Kentucky, the difference sometimes exceeding one percent of the total.
- Timeliness: Due primarily to the time spent waiting for other states to transmit intransfer records, plus the time spent to complete a final edit of the data, there is currently a delay of as much as two years in establishing a "complete" annual database. In addition, the time required to produce the numerous tables in the *Annual Vital Statistics Report* typically results in a delay in publishing the official data exceeding two years.
- Accessibility: The data are housed on a mainframe system requiring special software, such as SAS, for access. In addition, the arcane structure of the files and the coding conventions usually require a user to develop considerable familiarity with the data before useful analyses can be made. So far, funds have not been made available to develop an online query system.

#### Strengths of the Data

Registration of vital events is required by law, thus assuring that virtually 100% of events that occur in the state are reported. The system is fully population-based rather than relying on a sampling strategy. Electronic data have been maintained in a reasonably consistent format since 1977, and tabulated statistical data on births and deaths are available going back to 1911. Collection protocols and formats are similar among states, so the data are comparable.

## Vital Stats

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### Specific Uses of Information

- Provide data used to estimate population statistics by age, race, gender, and place of residence
- Provide birth and death statistics for a variety of purposes and programs of government, business, and other organizations
- Provide data to assess the health status of the population, e.g., birth weight, infant mortality, and leading causes of death, by both government agencies and other healthcare researchers
- Provide denominators for the calculation of rates and ratios of health events
- Provide data to the National Center for Health Statistics (NCHS) for incorporation into the National Vital Statistics System

### System Evaluation

The data are subject to computerized edit checks when entered. Corrections and amendments are made to the database on an on-going basis. The NCHS requires the state to maintain an error rate of no more than 2%. In addition, the Surveillance and Health Data Branch conducts a final check of the files prior to establishing the official annual database. Any anomalies are checked against the actual certificates.

### Suggested Data Citation

Kentucky Department for Public Health (KDPH). *Birth (or Death) Certificate Files*. Frankfort, Kentucky: Cabinet for Health and Family Services [data year].

## Youth Risk Behavior Surveillance System (YRBSS)

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**State Web Site:**

<http://www.uky.edu/RGS/PreventionResearch/yrbs2003/index.htm>

**National Web Site:**

<http://www.cdc.gov/HealthyYouth/yrbs/index.htm>

### Sources of Information for the YRBSS

The Youth Risk Behavior Surveillance System (YRBSS) is a questionnaire administered to students and is made possible by a grant to the Kentucky Department of Education (KDE) from the Centers for Disease Control and Prevention (CDC). Schools participating in the survey are selected randomly and participation is voluntary. Personal identifying information, such as name or address, is not collected. The YRBSS has been conducted in Kentucky since 1989. In recent years, the YRBSS has been implemented through a partnership between KDE and Kentucky Department for Public Health (KDPH), under the direction of University of Kentucky Center for Prevention Research. Local health department staff and partners administer the survey to students in typical public schools. In 2004, the survey was given to middle school students for the first time.

### Description of Data Collected

The YRBSS collects data on prevalence of health-risk behaviors among students, which are used to assess whether or not behaviors increase, decrease, or stay the same over time and if co-occurrences exist. To examine students' behaviors, the survey contains items related to unintentional injury and violence, tobacco use, and alcohol and other drug use. The questionnaire also includes items assessing sexual behavior, dietary behavior, and physical activity.

### Data Set Availability

YRBSS data from 2003 for high schools are available to the public. The data are available in both SPSS and comma delimited formats. Contact the YRBSS coordinator if requesting the raw data sets.

<b>2003 Sample Size</b>	1,693
<b>Smallest Geographic Level Released</b>	Statewide
<b>Cost of Data Set</b>	Free

### Data Publications

Once surveys are complete, the CDC includes results of all states that conduct the YRBSS in the Morbidity and Mortality Weekly Report. The 2003 Kentucky YRBSS results are highlighted in the latest report and can be found on the YRBSS website: <http://www.cdc.gov/HealthyYouth/yrbs/index.htm>. Detailed tables of the 2003 results can be found at the University of Kentucky Center for Prevention Research website: <http://www.uky.edu/RGS/PreventionResearch/yrbs2003/index.htm>.

### Data Limitations

YRBSS data is self-reported, and the extent of over-reporting or underreporting behaviors cannot be determined. Also, the data apply only to youth who attend school and, therefore, are not representative of all persons in this age group. Another limitation of the YRBSS is that parental permission procedures are not consistent throughout the state. However, a 2004 study by the CDC revealed that inconsistency in parental permission does not affect prevalence estimates as long as student response rates are high.

### Specific Uses of Information

- Determine the prevalence of health risk behaviors.
- Assess whether health risk behaviors increase, decrease, or stay the same over time.
- Examine the co-occurrence of health risk behaviors.
- Provide comparable data among subpopulations of youth.
- Monitor progress toward achieving the Healthy People 2010 objectives and other program indicators.

### Strengths of the Data

The schools taking the YRBSS are selected with double random sample selection. In two test-retest reliability studies of the YRBSS questionnaire done by the CDC, a majority of the prevalence estimates were not significantly different. The 2003 YRBSS had an overall combined school and classroom response rate of over 70 percent, making this data statistically representative of students in typical public high schools throughout Kentucky.

### System Evaluation

Before each biennial survey, sites (states and districts) and CDC work together to revise the YRBSS questionnaire to reflect site and national priorities.

**Suggested Data Citation**

Kentucky Department of Education (KDE), Kentucky Department for Public Health (KDPH), and Centers for Disease Control and Prevention (CDC). *Kentucky Youth Risk Behavior Surveillance System*. Frankfort, Kentucky: Cabinet for Health and Family Services, Kentucky Department of Education, [survey year].

## Youth Tobacco Survey (YTS)

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**State Web Site:**

<http://chfs.ky.gov/dph/ach/tobacco.htm>

**National Web Site:**

<http://www.cdc.gov/tobacco/>

### Sources of Information for the YTS

The Youth Tobacco Survey (YTS) is a questionnaire administered to middle and high school students in Kentucky and is made possible by a grant to the Kentucky Department for Public Health (KDPH) from the Centers for Disease Control and Prevention (CDC). Schools participating in the survey are selected randomly and participation is voluntary. Personal identifying information, such as name or address, is not collected. The YTS has been conducted biennially since 2000 by local health department tobacco coordinators and health educators. The YTS is also conducted nationally in even-numbered years with a sample size of approximately 300 schools in the United States.

### Description of Data Collected

The YTS collects data on prevalence of tobacco use among young people, including cigarettes, smokeless tobacco, cigars, bidis (hand-rolled cigarettes wrapped in a leaf and tied with string), and kreteks (clove cigarettes). The survey also collects information on secondhand smoke exposure, youth cessation of tobacco use, the role of media and advertising in tobacco use, minors' access to tobacco products, tobacco use in schools, tobacco-related attitudes of young people, and the influence of peers and family members to use tobacco products.



## Data Set Availability

YTS data from 2002 for both middle and high schools are available to the public. The data are available in both SPSS and comma delimited formats. Contact the YTS coordinator if requesting the raw data sets.

<b>2002 Sample Size</b>	1,535
<b>Smallest Geographic Level Released</b>	Statewide
<b>Cost of Data Set</b>	Free

## Data Publications

The Kentucky Tobacco Prevention and Cessation Program produces a report of the YTS results for every year the survey is administered. The 2002 YTS Report can be found at the Kentucky Tobacco Prevention and Cessation Program website: <http://chfs.ky.gov/dph/ach/tobacco.htm>.

## Data Limitations

The main limitation to YTS data is self-report bias. Therefore, the prevalence estimates are strictly based on each respondent's answers to the questions. The tendency to report a healthier lifestyle may occur. Another limitation is that no over-sampling procedures were taken in previous surveys so that regional data could be obtained. However, there are plans to over-sample in the 2004 YTS.

## Specific Uses of Information

- Monitor *Healthy Kentuckians 2010* goals
- Provide data to enhance the capacity of the state to design, implement, and evaluate the comprehensive tobacco control program.
- Provide data for tobacco grant applications
- To evaluate health disparities

## System Evaluation

The data collection is routinely monitored utilizing quality control standards developed by CDC. Evaluation of quality is determined through monthly and annual reports of these performance standards.

## Suggested Data Citation

Kentucky Department for Public Health (KDPH) and Centers for Disease Control and Prevention (CDC). *Kentucky Youth Tobacco Survey*. Frankfort, Kentucky: Cabinet for Health and Family Services, Kentucky Department for Public Health, [survey year].

### Strengths of the Data

The YTS provides data on risk behaviors associated with tobacco use across the state. The data collected are comparable to results from other states' Youth Tobacco Surveys and also to the national YTS results. Data from the YTS can be used to monitor components of CDC's Best Practices for Comprehensive Tobacco Control Programs, including surveillance and evaluation, community programs to reduce tobacco use, school programs, enforcement, counter-marketing, and cessation programs.

# Appendices

## Appendix A

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### Data Resource Tables

Included on the next two pages are tables containing a listing of certain public health topics and whether they are included in the data sources presented in this guide. Names of the data sources have been abbreviated to be included in the table. A listing of the sources and their abbreviation are included below.

Behavioral Risk Factor Surveillance System (BRFSS)

Central Nervous System Injury Surveillance Project (CNSI)

Child Fatality Review (CFR)

Childhood Lead Poisoning Prevention Case Management System (CLPPP)

Children's Oral Health Surveillance System (COHSS)

Crash Outcome Data Evaluation System (CODES)

Environmental Health Management Information System (EHMIS)

HIV/AIDS Surveillance System (HIV/AIDS)

Hospital Inpatient Discharge Database (HOSP)

Influenza Sentinel Surveillance System (ISSS)

Kentucky Birth Surveillance Registry (KBSR)

Kentucky Cancer Registry (KCR)

Kentucky Incentive for Prevention Student Survey (KIP)

Kentucky Trauma Registry (KTR)

Kentucky Women's Cancer Screening Program (KWCSP)

Perinatal Hepatitis B Screening (Perinatal Hep B)

Reportable Disease Surveillance System (RDDS)

Vital Statistics Surveillance System (Vital Stats)

Youth Risk Behavior Surveillance System (YRBSS)

Youth Tobacco Survey (YTS)

## Appendix A

DATA SOURCES																				
Topic	BRFSS	CNSI	CFR	CLPPP	COHSS	CODES	EHMIS	HIV/AIDS	HOSP	ISSS	KBSR	KCR	KIP	KTR	KWCSP	Perinatal Hep B	RDSS	Vital Stats	YRBSS	YTS
Alcohol	◆		◆			◆			◆		◆		◆	◆				◆	◆	
Arthritis	◆		◆						◆											
Asthma	◆		◆						◆										◆	◆
Brain Injury	◆	◆	◆			◆			◆					◆				◆		
Cancer	◆		◆						◆			◆			◆			◆		
Cardiovascular Health	◆								◆											
Congenital Anomalies (Birth Defects)			◆						◆		◆							◆		
Diabetes	◆		◆						◆		◆							◆	◆	
Environmental	◆		◆	◆			◆		◆		◆									◆
Fatality		◆	◆			◆		◆	◆		◆	◆		◆			◆	◆		
HIV/AIDS	◆		◆					◆	◆									◆	◆	
Hospitalizations						◆			◆		◆			◆						
Hypertension	◆		◆						◆		◆									
Immunizations	◆								◆							◆				
Influenza	◆		◆						◆	◆							◆	◆		
Injury	◆	◆	◆			◆			◆					◆				◆		
Lead			◆	◆					◆		◆							◆		
Maternal and Child Health	◆		◆	◆	◆			◆	◆		◆							◆		
Motor Vehicle Crashes		◆	◆			◆			◆					◆	◆	◆		◆		
◆ Topic included in data source																				

◆ Topic included in data source

Topic	DATA SOURCES																			
	BRFSS	CNSI	CFR	CLPPP	COHSS	CODES	EHMIS	HIV/AIDS	HOSP	ISSS	KBSR	KCR	KIP	KTR	KWCSP	Perinatal Hep B	RDSS	Vital Stats	YRBSS	YTS
Nutrition	◆																		◆	
Overweight / Obesity	◆				◆				◆									◆	◆	
Oral Health	◆				◆				◆			◆						◆		
Physical Activity	◆																		◆	
Public Health Preparedness	◆						◆		◆								◆			
Reportable Diseases			◆				◆	◆	◆	◆	◆				◆	◆	◆	◆		
Stroke	◆		◆						◆									◆		
Substance Abuse	◆		◆						◆		◆		◆					◆	◆	◆
Tobacco	◆						◆		◆				◆					◆	◆	◆
◆ Topic included in data source																				

◆ Topic included in data source

## Appendix B

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### Additional Resources

The public health data sources presented in this guide are very valuable to public health decision making. In many instances, however, to be most effective these sources need to be supplemented with population data as well as data pertaining to social and economic indicators. Listed below are specific links to certain national and state websites that will provide population and economic related data.

#### **Population Data**

U.S. Census Bureau <http://www.census.gov>

This is the main source for all population data. The most recent complete census was conducted in 2000.

Kentucky State Data Center <http://ksdc.louisville.edu/>

The Kentucky State Data Center website contains Kentucky related census data as well as population estimates for most recent years. Population data by county and Area Development District (ADD) are included.

#### **Economic Data**

Statistical Abstract of the United States <http://www.census.gov/statab/www/>

This document produced by the U.S. Census Bureau is a source for various social and economic indicators.

U.S. Department of Labor, Bureau of Labor Statistics <http://www.bls.gov>

This is a link to a source for data pertaining to employment, wages, and productivity.

U.S. Department of Commerce, Bureau of Economic Analysis <http://www.bea.gov>

This site contains information on various economic indicators including personal income by county, state and Metropolitan Statistical Area (MSA) level.

Kentucky Deskbook for Economic Statistics <http://www.thinkkentucky.com/edis/deskbook/>

The Kentucky Cabinet for Economic Development produces this site which allows the user to view and download various data tables pertaining to economic statistics in Excel or pdf format. For many indicators, data are included for county, ADD, and MSA.

### Glossary

**Area Development District (ADD)** - Kentucky has 120 counties that are divided into 15 ADDs for the planning of a variety of programs.

**Health Information Portability and Accountability Act of 1996 (HIPAA)** - These guidelines were developed to reform the healthcare industry by enforcing standards on health information, reducing fraud and abuse, and guaranteeing security and privacy of health care information

**Public Health Surveillance** - the ongoing systematic collection, analysis, interpretation and dissemination of health data. Specific types of surveillance are listed below.

- **Active Surveillance** - the health department regularly contacts reporting sources (e.g. once per week) to elicit reports, including negative reports (no cases)
- **Passive Surveillance** - a health jurisdiction receives disease or injury reports from physicians or other individuals or institutions as mandated by state law
- **Sentinel Surveillance** – This is a type of surveillance that determines cases from a certain sample of the population. Cases may be determined by active surveillance from specified sentinel providers, or these providers may provide information on cases to the reporting authority on a regular basis.

**Kentucky Behavioral Risk Factor Surveillance System (BRFSS)**

**Data Set Request Form**

Name: \_\_\_\_\_

Organization: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_

State: \_\_\_\_\_ Zip Code: \_\_\_\_\_

E-mail: \_\_\_\_\_

Telephone #: \_\_\_\_\_ Fax # \_\_\_\_\_

Year(s) of data requested: \_\_\_\_\_

Date project will begin \_\_\_\_\_

Date project will be completed: \_\_\_\_\_

Preferred Data Management Software (ex. SAS, SPSS, STATA) \_\_\_\_\_

How will data be used? Please specify topic(s) of interest: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_



The undersigned investigator agrees to the following with respect to BRFSS data sets:

I will not release the data set I receive to any other persons.

I will not use these data for any purpose other than statistical reporting.

I will not attempt to contact or re-identify any respondents to the survey.

I will acknowledge the Centers for Disease Control and Prevention (CDC) as the original source of the data.

I will send a copy of any published reports using BRFSS data to the address listed below.

Signed: \_\_\_\_\_

Date: \_\_\_\_\_

Note: Sample sizes for states and subpopulations vary. Estimates produced from fewer than 50 unweighted records are not considered by the CDC to meet standards of statistical reliability. It is highly recommended that 95% Confidence Intervals or standard errors be reported for all estimates produced by data users.

Please mail or fax this form to:

Kentucky BRFSS Coordinator  
Surveillance and Health Data Branch  
Kentucky Department for Public Health HS2E-D  
275 East Main St.  
Frankfort, KY 40621

Phone # (502)- 564-3418      Fax # (502) 564-0542

## Appendix E

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### Agreement for Use of Kentucky Health Claims Data

This agreement between the Kentucky Department for Public Health, Health Policy Development Branch, and the individual whose signature appears below, applies to all health claims data collected in compliance with KRS 216.2920-216.2947, including but not limited to subsets of patient level records in full or in part, and any and all summaries or aggregations of data which may be derived from original data or any subset thereof.

*Personal identifiers:* Patient level health claims data have been purged of name, address, social security number, and other direct personal identifiers to prevent individual patient identification. Nevertheless, the undersigned agrees that no attempt will be made to identify individual patients through any means or methods without expressed written permission of the Kentucky Department for Public Health. Furthermore, the undersigned agrees that information derived or summarized from patient-level data which could result in the identification of any specific individual will not be released or made public.

*Establishment identifiers:* Identifiers for hospitals, clinics, physicians, and other health care providers have been included on patient level records in compliance with the aforementioned statute for the purpose of making cost, quality, and outcome comparisons among providers. Such purpose does *not* include the use of information concerning individual providers for commercial or competitive purposes involving those providers, or to determine the rights, benefits, or privileges of such providers. Providers shall not be identified directly or by inference in disseminated material. Under this agreement, users of data shall not contact providers for the purpose of verifying received data or summaries derived therefrom.

The undersigned gives the following assurances with respect to data obtained under the terms and conditions of this agreement:

- ☐ I will not attempt to link or permit others to attempt to link the hospital stay records of persons in this data set with personally identifiable records from any other source without prior written approval from the Kentucky Department for Public Health;
- ☐ I will not attempt to use or permit others to use the data sets to learn the identity of any person included in any set;
- ☐ I will not release or permit others to release any information based on these data that identifies individuals, either directly or indirectly;
- ☐ I will not attempt to use or permit others to use the data to learn the identity of any provider that may be represented in the data;
- ☐ I will not contact or permit others to contact providers or persons represented in the data;
- ☐ I will not use or permit others to use data concerning individual health care providers
  1. for commercial or competitive purposes involving those providers,
  2. to determine the rights, benefits, or privileges of individual providers, or
  3. to report, through any medium, data that could identify individual providers, either directly or by inference;

- ☐ I will require others in the organization specified below who use the data to sign this agreement and will keep those signed agreements and make them available upon request;
- ☐ I will not release or permit organizations or individuals outside my direct control or the control of the organization specified below to release the data sets or any part of them to any person who is not a member of the organization specified below;
- ☐ I will make no statement nor permit others to make statements implying or suggesting that interpretations drawn are those of health care providers that may be identified in the data, either individually or as a group, or the Kentucky Department of Public Health; and
- ☐ I will acknowledge the "Kentucky Department for Public Health, Health Policy Development Branch" as data source in any and all publications based on these data.

Violation of this agreement will result in action by the Kentucky Department for Public Health. Violations deemed unlawful may be referred to the Commonwealth Attorney, the police, the Federal Bureau of Investigation, or other appropriate legal authority for investigation and/or prosecution.

**Note: The person signing this data use agreement must be the person to whom the data product is shipped.**

Signed: \_\_\_\_\_

Date: \_\_\_\_\_

Print name: \_\_\_\_\_

Organization and Title: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ ZIP: \_\_\_\_\_

Telephone: \_\_\_\_\_